Development of a Health Educational Game for Children with Chronic Kidney Disease: Use of Focused Interviews to Gauge Interest and Preliminary Topics

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Abstract:

Background: Although there has been some research looking into the use of games for the education of pediatric patients, the literature has been scarce regarding the adaptation of games for parental education.

Objectives: The main objective of this systematic literature review is to examine the publications concerning the use of games or interactive media in the education of parents of children with chronic conditions.

Data Sources: Two investigators conducted a systematic review of the literature according to the Preferred Reporting Items for Systematic Review and Meta-Analyses (PRISMA). We focused on the use of interactive media and video games to educate parents of children with chronic conditions.

Study Eligibility: We included cohort studies, randomized control trials, and observational studies in the search of the literature.

Study Appraisal and Synthesis Methods: Overall trend in the results and the degree of certainty in the results were considered when assessing the body of literature pertaining to our focused questions.

Results: Our initial search identified 4352 papers, but only five fulfilled the criterion established for final analysis.

Conclusion: We found limited evidence of the effectiveness of using serious games and or interactive media to educate parents of children with chronic conditions. Consistency of positive results supports the idea that parent education is possible through interactive media or games. The magnitude of this effect cannot be accurately determined from the studies reviewed. The

effects that were shown on knowledge add to the causal linkage since parent knowledge has been associated with health outcomes in pediatric patients with chronic conditions.

Introduction:

The estimated prevalence of chronic health conditions in children is 15 to 18 million in the United States. [1] These children depend on parents/caregivers for the majority of their care and health management, until they have developed the skills to self-manage their condition(s). The parent/caregiver role may include administering medications, ensuring that the child performs procedures and providing transportation to appointments with health providers.

The number of adults who have grown up with technology, in particular interactive media such as computer-delivered education and video games, has been rising with each successive generation. Although the use of computer-based technology and video games has been described as a means to teach children to self-manage conditions such as cancer, asthma, and diabetes, the use of interactive technology and/or video games to teach parents about their children's conditions has not been well characterized. [2-5] The goal of this systematic review of the literature was to identify interactive media approaches used to educate parents of pediatric patients with chronic conditions and their relative effectiveness.

Methods:

Based on the Preferred Reporting Items for Systematic Review and Meta-Analyses (PRISMA) criteria, two co-authors conducted a review of publications using the following search engines MEDLINE, INFO, CINAHL, and EMBASE. [6] The search terms used are presented in Table 1. We focused on one research question: *Does the use of serious games (games intended to educate) and or interactive media in parents improve health outcomes in*

children with chronic conditions (e.g. asthma, diabetes, chronic kidney disease, cystic fibrosis, and cardiac abnormalities)?

The criterion emphasized any observation, educational intervention or randomized control trial using either interactive media or interactive games for parents of children. The titles of the articles were scanned to identify pertinent studies and interventions. We determined the studies' population, intervention, comparator, outcome, time allowed for outcomes, time of search of the literature, and study designs allowed (PICOTTS criteria- Table 2). Two authors examined abstracts from the most relevant articles. They also drew additional papers from a hand search of references.

When available, we determined internal validity, potential for biases, accuracy and appropriateness of the analysis and applicability used in each study. We also determined the literacy level of the tools used in these the studies using the Flesh-Kincaid scale.

Inclusion/Exclusion Criteria:

Only observation and randomized control trials were included in the final literature review. We decided on this type of manuscript because of an absence of a large number of randomized trials in the literature that pertained to the topic. We divided the studies into "good, fair and poor quality" criteria. A "good study" had a large enough effect or was highly certain. A "fair study" either had fair certainty and or had a fair effect size. A "poor study" had poor certainty of effect and or no effect. We included studies that went as far as 1986, the year this topic was introduced in the literature. [7] For cohort and randomized trials, we did not differentiate studies on the basis of time between intervention and post-testing, when applicable. The participants for the studies needed to include parents in the exposure group.

Data Extraction:

The studies were examined and basic information was extracted from each study. For quantitative studies data was collected on: (1) sample size; (2) composition of the study population; (3) measurement tool(s); and (4) outcomes.

Critical Appraisal:

Two co-authors critically appraised each manuscript based on previously established criteria (9) to assess the size of each study as well as potential biases, confounders, measurement precision, generalizability, and the meaning of the study findings. Studies that included qualitative data were appraised using key questions (Appendix 1).

Data Synthesis:

The variation in the study designs did not lend the data for meta-analysis. Qualitative assessment of the studies was performed based on the criteria established by PRISMA. [6] The overall trend in the results and the degree of certainty in the results were considered when assessing the body of literature pertaining to our focused questions.

Results:

Our initial search identified 4352 papers, but only five fulfilled the criterion established for final analysis (Figure 1). [8-12] Most of the studies that explored knowledge and/or skill showed an improvement in these outcomes after implementation of their particular intervention (Table 3).

One study examined the level of knowledge that parents had regarding asthma and found an improvement in scores using the tools presented in the study. [9] This study did not control for child's percentage of life with the condition, so parents experience with the disease or knowledge base overtime was not evaluated. The questions used to assess participant knowledge pre- and post- intervention appeared to have a literacy grade level that varied greatly. This variation in grade level amongst the tools may have been another source of measurement bias.

Another study used qualitative methods in the form of essay responses to gauge the perception of parents and patients about a diabetes education portal. [8] The study provided a clear explanation of their methodology for data analysis. The investigators reported that the web portal allowed participants to locate answers to questions that were of interest to them. Some of the responses noted low interaction by providers on the web portal.

One randomized study used human simulators for improving the knowledge and management of diabetes by parents. [10] Although this was a small cohort study, improvement in self-efficacy and knowledge were promising, but not statistically significant. This study did not include information on the child's disease duration.

The largest study we found was an observational study that looked at the use of educational kiosks at various public locations, including the frequency of use and topics examined by users. [11] This study described that participants found this form of interactive media to be educational. In the study, 49% of the first time users who completed the exit survey planned to discuss the topics presented through the kiosks with health providers. Although the study does not present the questions used within the kiosk, there was no association between the ease of kiosk use and not having high-school education. Almost half of the kiosk events (47%) retrieved during the study came from one location, which could have acted as a source of selection bias since participants in that location (a fast food restaurant) could have different exposure level than those recruited in a library.

The next randomized study assessed the effect of intense therapy with dieticians, psychologists and providers on the self-management skills of parents whose children were diagnosed with atopic dermatitis.[12] The intervention showed improvement in medical treatment confidence by the caregivers, resulting in a greater reduction (although not statistically

significant) in disease severity among the intervention participants. Based on the SCORAD (a survey for scoring atopic dermatitis) the intervention arm had a decrease of 20.5 points versus 16.2 points in the control arm ($p = 0.21$). The clinical significance focused on the reduction in rumination from the caregivers following the intervention. This reduction in rumination would allow parents to focus on the more pertinent aspects of their child's chronic condition. To measure rumination the authors relied on the Trier scale for measuring coping with disease, but there are not actual values provided for the intervention and control arms of the study. Additionally the reduction in rumination allowed for the discussion of issues that arise without the distraction of previously addressed topics.

Discussion:

We found limited evidence on the effectiveness of using serious games and or interactive media to educate parents of children with chronic conditions. However, a consistency of positive results supports the idea that parent education is possible through interactive media or games. The magnitude of this effect cannot be accurately determined from the studies reviewed above. The effects that were shown on knowledge add to the causal linkage since parent knowledge has been associated with health outcomes in pediatric patients with chronic conditions. [13]

It is important to understand the ability of parents to receive and process health information for the management of their child's chronic condition. To optimize this capacity, parental education should be tailored to their needs, culture and literacy level. It has been shown that parents go through a sense of disorientation when their child is diagnosed with a chronic condition. [14] Afterwards it may be expected that parents or caregivers will be responsible for the management of their child's chronic condition until the patient is ready to self-manage their health.

Interactive and game platforms for parent education may be appealing because they can draw on skills that parents developed in their youth. These parent education media could also help account for low parental health literacy as the information could be presented with visual and auditory signals, promoting disease knowledge and management and impacting patient health outcomes

Looking through the lens of social learning theory there are three goals that must be obtained so that self-management can be successful. Firstly, cognitive and behavioral coping skills that must be mastered in order to meet the challenging demands that arise during the course of the disease. Secondly, there needs to be an emphasis on personal efficacy and the enhancement of expectations of success. Finally the patient, as well as their caregivers, should be able to manage stimulus conditions in social and physical environments to aid symptom management as much as possible. [15]

The positive and/or informative findings in the studies analyzed may be a reflection of publication bias in that only positive findings appear to be reported. Although this is a legitimate concern, the scarcity of studies noted shows a gap in the literature regarding the use of interactive media for parents as learners of their child's chronic condition. This gap represents an opportunity for improving the knowledge base of the primary care giver of children with chronic health and mental conditions. Serious games are one tool that would allow parents, as well as children, to develop their self-efficacy skills.

From our systematic search of the literature, the studies were underpowered for the most part. This lack of large cohorts is another area that can be improved upon in order to strengthen the body of evidence. It may be argued that the lack of large cohorts makes the findings in the studies described statistically insignificant. While this may be technically true, these small

studies show some trends that may become more evident with larger studies. Additionally, the clinical significance of findings in each of the studies, were taken into consideration. The increased knowledge that caregivers can gain from the use of interactive media and or games has been shown to translate into decreased use of health care. [16]

The improved self-efficacy of the caregiver may transfer to the child. One plausible sequence of events is that the child sees their caregiver gaining a handle on the information relating to their chronic illness. From there the child is inspired to learn about their illness so that they may emulate their caregiver.

The literature has few studies that show improvement in intermediate measures of disease management for parents of children with chronic conditions. The lack of measures of health outcomes, such as morbidity from disease and or health care utilization serve as potential avenues for future research. Few large interventional studies also points to a gap in the current literature. While there does not appear to be a large amount of existing data, the evidence that is present has encouraging results.

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Appendix 1: Key Questions for Qualitative Studies

Was the sample used in the study appropriate to its research question?
Were the data collected appropriately?
Were the data analyzed appropriately?
Can I transfer the results of this study to my own setting?
Does the study adequately address potential ethical issues, including reflexivity?
Overall: is what the researcher did clear?

Figure 1: PRISMA Flow Diagram

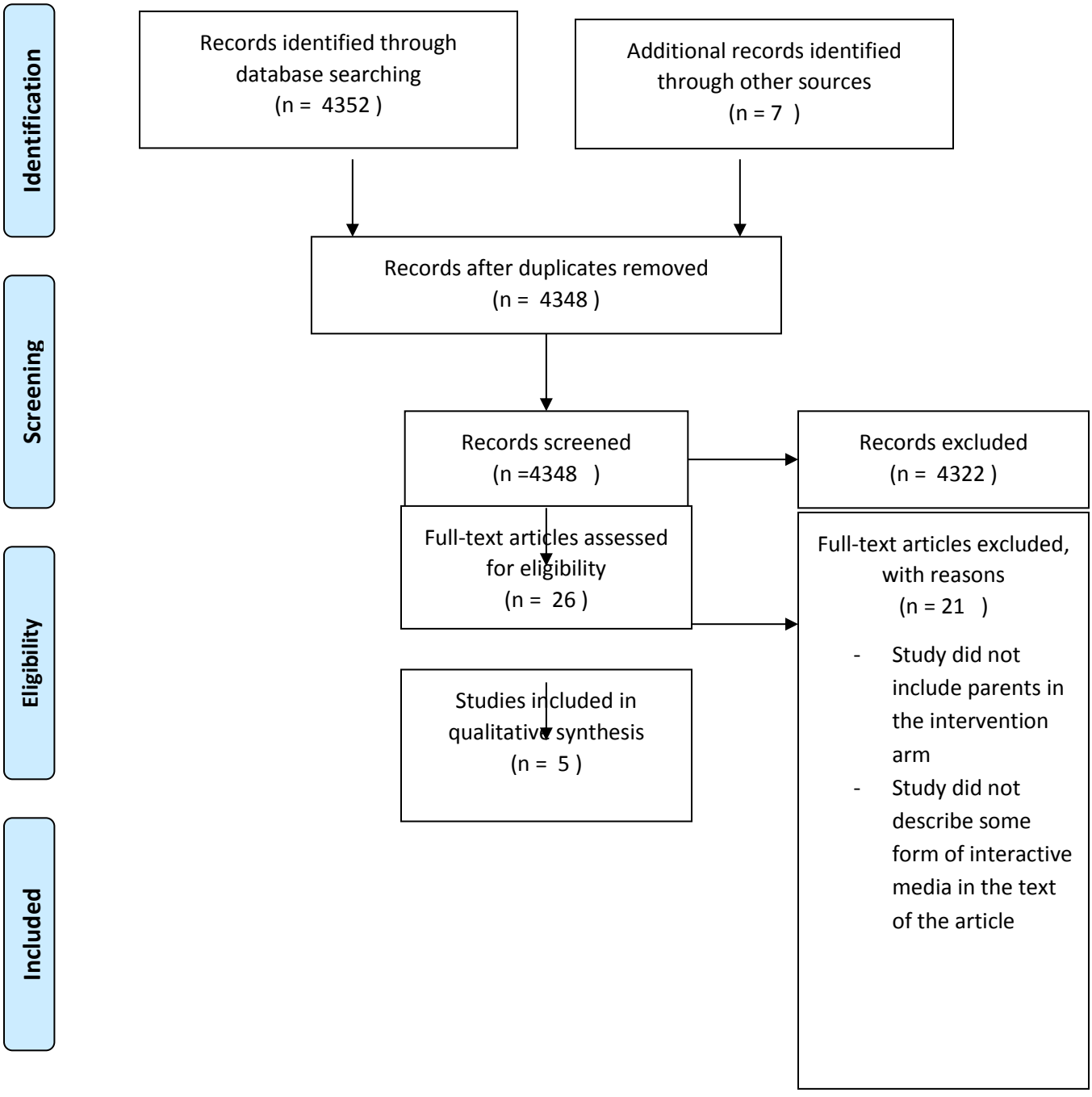

Table 1. Search Terms: Search Strategies and Key Words

Database	Search Strategies and Key Words
Pubmed	"(parent education) AND (chronic condition OR diabetes OR asthma OR Chronic kidney disease OR Cystic fibrosis OR Congenital heart disease OR CANCER) AND (interactive media OR game OR interactive tool)" parent education AND (chronic condition OR diabetes OR asthma OR Chronic kidney disease OR Cystic fibrosis OR Congenital heart disease OR CANCER) AND (computer OR software)" "(parent* education OR parent learning) AND (chronic condition OR cancer OR diabetes OR CF OR congenital heart disease OR chronic kidney disease OR asthma OR chronic illness) AND (interactive media OR game* OR video games OR serious games)" parent education AND (chronic condition) (parent education) AND (chronic condition OR diabetes OR asthma OR Chronic kidney disease OR Cystic fibrosis) (serious games OR game* OR interactive media) AND (chronic illness OR diabetes OR chronic kidney disease OR cystic fibrosis OR cardi*) AND (parent*)
EMBASE	'video game' OR 'video games'/exp OR 'video games' OR 'video gamer' OR 'video gamers' OR 'video gaming' OR videogame OR videogames OR videogamer OR videogamers OR videogaming OR'computer game' OR 'computer games' OR 'computer gamer' OR 'computer gamers' OR 'computer gaming' OR 'online game' OR 'online games' OR 'online gamer' OR 'online gamers' OR 'online gaming' OR 'game system' OR 'games system' OR 'gamer system' OR 'gamers system' OR 'gaming system' OR 'game systems' OR 'games systems' OR 'gamer systems' OR 'gamers systems'OR 'gaming systems' OR 'arcade game' OR 'arcade games' OR 'arcade gamer' OR 'arcade gamers' OR 'arcade gaming' OR playstation OR playstations OR 'interactive game' OR 'interactive games'OR 'interactive gamer' OR 'interactive gamers' OR 'interactive gaming' OR gamer OR gamers OR 'game console' OR 'game consoles' OR 'gaming console' OR 'gaming consoles' OR 'digital game'OR 'digital games' OR 'digital gamer' OR 'digital gamers' OR 'digital gaming' OR 'handheld game' OR 'handheld games' OR 'handheld gamer' OR 'handheld gamers' OR 'handheld gaming' OR'console game' OR 'console games' OR 'console gamer' OR 'console gamers' OR 'console gaming' OR multiplayer OR multiplayers OR gameplay OR gameplayer OR gameplayers OR gameplayingOR 'game boy' OR 'game boys' OR 'game cube' OR 'game cubes' OR nintendo OR xbox OR mmorpg OR atari OR 'space invader' OR 'space invaders' OR 'death race' OR 'pac man' OR battlezone ORastrocade OR 'donkey kong' OR coleco OR tetris OR 'super mario' OR 'sonic the hedgehog' OR 'street fighter' OR 'mortal kombat' OR pokemon OR frogger OR dreamcast OR 'grand theft auto' ORsega:ab,ti OR pong:ab,ti AND ('parents'/exp OR parents OR 'parent'/exp OR parent) AND ('education'/exp OR education OR 'learning'/exp OR learning) "parent* AND (education/exp OR education) AND ((interactive AND media) OR interactive OR serious) AND games AND ((((chronic AND conditions) OR diabetes/exp

	OR diabetes OR asthma/exp OR asthma OR cancer/exp OR cancer OR congenital) AND (heart/exp OR heart) AND (disease/exp OR disease)) OR cf OR chronic) AND (kidney/exp OR kidney) AND (disease/exp OR disease)"
EBSCO	"parent* education AND (chronic conditions OR cancer OR congenital heart disease OR diabetes OR asthma)"
CINAHL	"(parent education OR parent learning) AND (games Or interactive media)" parent* AND (chronic illness OR diabetes OR ckd OR chronic kidney disease OR cardiac OR cystic fibrosis) AND (interactive media OR game* OR serious games)
Web of Knowledge	Topic=(parent* education) AND Topic=((chronic condition OR diabetes OR asthma OR CKD OR CF)) AND Topic=(interactive or simulation) (parent* education) AND Topic=(user-computer interface) Topic = (parent education OR parent*) AND Topic=(educate OR educating) AND Topic=(parenting OR disciplining) AND Topic=(chronic condition OR diabetes OR CKD OR chronic kidney disease OR asthma)

Table 2. Population, intervention, comparator, outcome, time allowed for outcomes, time of search of the literature, study designs allowed (PICOTTS)

Population	Parents of children with chronic illnesses (includes asthma, diabetes, chronic kidney disease, cardiac abnormalities, and or cystic fibrosis)
Intervention	Serious/educational game; interactive media
Comparator	Parent's knowledge about their child's condition at baseline or in control group
Outcomes	Markers of improved management of the child's disease; parental knowledge; disease severity; health outcomes
Time allowed for interventions effect	Up to 1 year of time allowed between intervention and post-test if applicable
Time into the past for the search	1986 was the furthest back in the literature for the search
Study designs allowed	Cohort studies; RCTs; observational studies

Table 3: Synthesis Table

Study Authors	Population, design, intervention (tools) and Outcome	Findings	Literacy level of tools (Flesch-Kincaid Grade Level)	Assessment of Quality
Fall AJ et al 1998	**Population:** 20 parents of children with asthma. **Design:** intervention (pre and post assessment) **Intervention:** Interactive, computer-based program; **Outcome:** Newcastle Asthma Knowledge Questionnaire	10 parents showed improved performance; 3 parents showed no change; 4 parents showed declined performance 3 dropped out	**Intervention tool**: n/a **Outcome measure**: Newcastle Asthma Knowledge Questionnaire ranged from 2.2 to 11.9 grade level	Mixed results study; Fair quality study
Nordfeldt et al 2010	**Population:** 19 parents and children **Design:** Intervention (pre and post assessment) **Intervention:** 24 essays responses (Response rate 8.5%) **Outcome:** Portal evaluation	Respondents found that the portal was a good source of "reliable and current information"	**Intervention tool**: 5th grade reading level.	Qualitative study findings give an important view of parental/child perception. Fair quality study
Sullivan-Bolyai et al 2012	**Populations:** Parents: (10 in pilot, 13 in focus groups and 16 in intervention) **Design:** Intervention (pre and post assessment) **Intervention:** Interactive human patient simulators **Outcome:** Change in Diabetes Awareness and Reasoning Test	Improved parent score	n/a	The internal validity of the study was good; randomization occurred in the pilot arm to limit potential confounders but small cohort that was randomized
Thomps	**Population:** Inner city	Increased interest		Fair quality

on et al	population at a library, a Department of Motor Vehicles office, and a fast food chain location **Intervention:** Use of an information kiosk **Outcome:** Interest in using the information provided from the sessions 1846 sessions of informational kiosk use	of using of information provided and desire to discuss topics with health care providers		observational study; Skew of results from one site but large sample population
Wennin ger et al 2000	**Population:** 129 families of children with Atopic Dermatitis **Intervention:** Combination of psychological counseling in addition to clinic visits **Outcome:** Disease severity, Quality of Life of the parents, and coping skills of parents and patients	Increased confidence and decrease in rumination through intensive behavior therapy intervention		Good internal validity of the study, but concerned about the lack of tables comparing the baseline characteristics of the intervention and control groups within the study

Table 4: Critical Appraisal of Qualitative Study

Article Citation	Appropriate Sample population	Data Collection	Data Analysis	Transferability of results to our population	Addressing potential ethical issues	Is it clear what the research did
Nordfeldt et al 2010	Sample was 24 (only 20 had used the portal) individuals who responded from a set of 484 invitations letters sent; all were either patients or their parents who were seen in two pediatric clinics in Southeastern Sweden; sample was a good representation of the group interest	Invitations were sent to 484; only 24 people sent back the essays response that were asked for	Analysis of the essays was done in a clear and logical manner. Two authors read the primary data then explored unclear statements. They had a clear time-out session before reproaching the data.	The study population was homogenous since this is Sweden, but the idea of obtaining the perspective of those who would use an online resource like this.	There was not a discussion of ethical concerns in the study	It was clear what the researchers did, especially the methodology for analyzing the data.

Table 5: Evidence Table

Citation	Study Question and Research Design	Study Population (descriptive: demographics, eligibility criteria) and how chosen (volunteers, recruitment, tertiary care clinics, population-based, etc)	Initial Comparability of groups (ie, randomization or group composition; concealment of allocation)	Drop outs (no endpoint data), adherence, crossovers (attrition, loss to follow up)	Potential for selection bias (+ to +++) and explain	Measurement of exposure, intervention, potential confounders, and outcomes; reliability and validity of measurement; how performed, blinding	Potential for measurement bias (+ to +++)	Potential confounders (name and describe how each was controlled for)	Potential for confounding (+ to +++)	Analysis (intention to treat or other adjustment)	Results: magnitude and direction (point estimate; random error or precision (confidence interval); statistical significance	Clinical and Public Health importance for the source population; for a wider population	Overall judgment of internal validity (good, fair, poor)	External validity: applicability to other populations
Fall et al1998	Does the use of an interactive computer program improve the asthma knowledge of parents of asthmatic children? Cohort	Parents had to have had children that were seen in the clinic or wards at least once before, child had to have a definite diagno	20 parents agreed to be in the study	3 parents did not complete the "post" questionnaire	rating is ++; no information given on where the hospital used for the study was located may have been a private hospital or public one	The questionnaire used has been validated in previous studies; no blinding needed since this was a cohort study looking for an improvement in score	Rating +; same questionnaire used before and after the intervention	potential confounder is the fact that parents had seen the questions before the intervention, and they may have looked up the	Rating is ++, did not show an attempt to control for confounding	Looked at change in overall score for those who returned the post-intervention questionnaire; also looked at changes in response to individual questions	Mean pre-test score was 21.8, post-test score mean was 23.5 (SD of 3.9, P = 0.06); 10 of the 17 improved their knowledge	The change in test scores was rather small at 1.6, and such a change may not correlate to better care given by parents on a daily basis and during exacerbations	internal validity = fair, there was a change in test scores, this change was not statistically significant nor was it likely clinically significant	The program may work as an education tool for the general population since the parents in the study did enjoy using it, and the increased knowledge would be of benefit to the general population (they might know someone who has asthma or encounter someone with

	study of parents in the outpatient clinics of a children's hospital; parents given baseline questionnaire (Newcastle Asthma Knowledge Questionnaire) then given time to go through the interactive program (Breathe-Smart tm). 1 month later the parents were sent the	sis of asthma; English as first language used by parents ; parents were chosen among those who came to the outpatient clinics				(which reflects knowledge base);		information later on, which may have artificially inflated the results; parents were also in the clinic after their child had had an acute asthma exacerbation that may have required a hospitalization, so they could have had previous education while in the hospital			after using the computer program, 3 had no change in knowledge scores, and 4 showed a decrease in their scores			asthma in the future)

	same questionnaire and asked to mail it back with their responses; using previous study a high-knowledge group would have a score of 25.3/31, a sample size of 20 would have more than 90% power in detecting a score improvement of 15%													
Sullivan-Bolyai, et al 2012	explore concept of teaching parents with human	Parents of children with type I DM were included in	In pilot group 2 there was randomization done to the	No dropouts or loss to follow-up were mentioned	Selection bias = ++; small number of participants drawn from a	Used the Diabetes Awareness and Reasoning Test-Parents	Measurement bias potential = +; scales used are in the literature,	Education level of parents may influence how well they	Confounding bias = +; randomization would have reduced possible confounde	Note-based techniques were used for the focus groups; clarified with	For the Diabetes awareness and reasoning the	the changes in scores was in the predicted direction; shows that interactive modalities	Internal validity was good; randomization of the pilot arms helped to hopefully distribute the sample	External may be fair; the pilot population had a higher level of education, so this may not accurate

	patient simulator (HPS) and teach parents management education for newly diagnosed TIDM with HPS	the focus groups; parents of children who had been diagnosed in the past year were used for the pilot groups	control (8 in the control and experimental arms each); in pilot group 1 they recruited English speaking parents of children with DM for at least 1 yr (got 10 parents in a 1mo recruiting period); majority of participants were from university based Pediatric Diabetic Clinic in Worce		similar environment in the university based clinic; no demographic data given to explore this further; also enrolled people on a rolling basis	to measure parent knowledge (eliminated insulin-specific questions so it went from a 47-item multiple choice questionnaire to a 38 question tool); asked for Wysocki's modified problem-solving measure that they then adapted to measure parental problem-solving abilities and knowledge synthesis; used the Self-efficacy for	have been proven in other studies	interact with the simulation practices; socioeconomic status of parents may also act as confounding; randomization in the 2nd pilot group would have controlled for this	rs in the 2nd pilot group	participants and recording tapes; for the focus groups looked for consensus in topics throughout the 2 groups to frame pilot studies; for the pilot studies collected quantitative data that was double-entered, got means and standard deviations for continuous variables; differences between groups were compared using repeated measures for continuous variables	experimental arm had a 16 point increase in their scores from baseline, control group had a 16 point group in their scores from baseline (p=0.94, F of 3.15); for problem-solving measure the experimental group had a 8 point increase in their scores, control group had a 7 point increase in their	of learning can be of use when teaching parents complex skills for the management of a chronic condition in their child	population well; tools used in the study showed good reliability	represent the general population

			ster, Massachusetts; for pilot study group 2 the mean age of parents was 42 yr, had 13 female caregivers and 3 male caregivers, 15 white and 1 Latina; mean 15.4 yrs of education			Diabetes 22-item Likert-scale instrument to look at parents' confidence in caring for children with T1DM; used Hypoglycemia Fear Survey-Parents to measure parental fears and avoidance behaviors associated with hypoglycemia in their children; State-Trait Anxiety Inventory to measure situational (at the tendencies and					scores (F = 0.00, p = 1); for STAII - state scores the experimental group had a 5 point decrease in their scores while control had a 3 point decrease in scores (lower scores meant less state anxiety, F = 0.19, p =0.67); for STAII-Trait scores the experimental arm had a 3 point decrease in scores while control arm			

						stable tendencies (general feelings) toward anxiety					had no change in scores (lower scores meant less trait anxiety; F = 1.9, p=0.18); Self-efficacy diabetes scores increased by 8 for experimental arm and increased by 6 for control group (F = 0.17, p = 0.68, higher scores meant more confidence in diabetes care); for hypoglycemi a fear-survey the			

											experimental group had a 5 point decrease in scores while the control group had a 7 drop in scores (F= 0.03, p =0.87, lower scores meant less fear; For focus groups parents wanted vignettes to include treating hypoglycemia with glucagon injections and washing hands before rechecking			

											glucose with monitor; learning process should have 2 phase (1st dealing with mechanical and survival skills, 2nd starting to think more complex and abstractly for parents); good reliability demonstrated with the instruments used for the study			
Thompson et al 2007	examine the use of touch screen health kiosks	Urban setting in Seattle, Washington.	refer to previous square, cut and	there were no dropouts given the	Rating for selection bias is at least++, the people	kiosk event = person logging onto the kiosk and id	Rating for measurement bias is +; gathering frequenc	Confounding could result from socioeconomic	Rating for confounding is +++ because there is the possibility	analysis involved obtaining frequency distributions and	1846 sessions, only 1447 used for	Very high potential for public health use; provides a way to present	Internal validity was barely fair; lots of possibility for confounding, but this was	Very applicable to general population since the study population

	in low-income urban setting; kiosks contained health information on promoting child-health descriptive study of the use of health kiosks	3 kiosk set up at a community settings; a McDonald's, a public library, and a Department of Motor Vehicles (DMV) office. The population around this area was 20-25% under the age of 14; 49-65% had a high school education or less for adults; 26-32% parents are single	paste the information into this block	study design, more of an observational study	who would visit a McDonalds would provide more data points given that more people would be there than at the DMV or the library	self as new or previous user; user would id self as adult or not, only self-identified adults would be have their data used in the study; users would identify a month and year of birth for the index child, then they would get modules that were appropriate for that age group for 9 of the 14 modules there was a set of questions that risk	y data that should be reliably obtained, some concern if kiosk fails; no other problems seem apparent	status playing a role in the data obtained from McDonalds since people who would be eating there would not necessarily have a lot of options in general. This relates to the population that would be commonly found in the library, and thus use the library based kiosks. The differences in populations may skew the	to difference between the populations that would provide data from the various locations; study did not mention attempts to control for this in the analysis	chi squares to determine statistical significance; focused on first time users for most calculations as a way to reduce double-counting in analysis ; Poisson regressions were used to evaluate for relationship between characteristics and kiosk choices, also used from relative risk	analysis; 399 were previous users (22%), 1/2 of all kiosk sessions came from McDonalds (873, 47%), 642 were at the public library (35%), and 331 at the DMV (18%); 48% (117) of first time users who did the exit survey said they had high school education or less; 26% (67 people) of	health information that can be tailored to an individual's needs in the community setting; nearly 1/2 of first-time users said that they would use the information they learned to discuss a topic with their physician;	an observational study; concern for confounders, one location provided 47% of all sessions	represented a good sampling of the general population (1/4 of people without internet access and 1/4 with less than a high school education)

						stratified the index child prior to starting the module, this was used to guide messages given to users in case the child warranted further evaluation; there was an exit survey that looked at ease of use, newness and usefulness of information provided, whether the information would be used to guide a discussion with the		results that each location provides			users to answer exit survey said the never used the internet; TV/media (16%, 235 people), smoke exposure (14%, 196), ADHD screening (12%, 180 people), and asthma (11%, 155 people) were the most commonly visited modules for first time users; only 1 module was explored			

						child's provider, whether or not they would try some of the things brought up in the modules, child's health on a Likter scale, and highest level of education of the user, and frequency of internet use					during the first time use in 61% of the sessions (882), 13% of users viewed 2 modules, 6% viewed >= 3 modules; During the option exit survey 405 of first time users responded to >= 1 question, of this group 155 (57%) found the kiosks easy to use, 26% (64) found the kiosk hard to use;			

											ease of kiosk use was associated with internet use w/ a prevalence ratio of 1.46 (95% CI of) 1.09-1.91) but not above high school education VS less (PR of 1.04, 95% CI of 0.81-1.34); 66% (n = 165) of respondents found information new, 66% (n=168) found the information useful; 55% of respon			

											dents (n=127) said they planned to try what they read in the kiosks; 49% (n=113) said they plan to talk with their physician about the things they learned from the sessions; users with at-risk children did not vary according to grade level (p=0.72) or internet use (p=0.64); no difference in previo			

											us users for grade level (p=0.18) or education (p=0.71) for at-risk children; previous users were more likely to view >=2 modules (PR = 1.38, 95% CI 1.13-1.69); kiosk in public library had more previous users (35% of all sessions at that location) than DMV (19% and McDonalds			

											13%, p<0.001); first time users at DMV were more likely to explore >= 2 modules (p=0.002) ; use at the 3 locations did not vary according to grade level or internet use; number of at-risk children for first time users or selection of modules did not vary by location of kiosk			
Wenni	Struct	129	Rando	No	Selection	SCORA	Measure	Time	Potential	They did	SCOR	This	Internal	External

nger et al 2000	ured education program for parent groups that aims at increasing parents' self-management skills in managing atopic dermatitis (AD); cohort study with a control group with randomization into intervention arm or 1 year waiting control group; intervention was very intensive with psychologist, pediatr	completed cases (63 families in the intervention arm and 66 control families); recruited 204 families from Berlin area; mean age of children was 3.1 yrs (SD = 2.2), mothers ages ranged from 25-44 (mean =32.7, SD =3.9); mothers had a mean 11.4 years of school education (SD = 1.6 yrs), 40%	mization was done, according to them there was not any significant differences between the two groups, but no table provided to truly assess this.	mention of drop outs are mentioned, have only completed 129 cases out of 204 families recruited	bias potential = +; parents for both the control and intervention groups were drawn from the same sample population; the people who were recruited may have been bias in which families were approached; no information on allocation concealment	D-score is a means of measuring AD disease severity that has been used in literature before; used a Quality of life in parents of children with AD (disease specific questionnaire that has been shown to work in the literature) to assess health related quality of life ; also used Trier scales for measuring coping with disease to assess	ment bias potential = +; the scales used for assessing disease severity, quality of life, and coping styles have been used in the literature before	since diagnosis may have an effect on how well the parents may be able to cope with stressors in their child's life and how it relates to their AD; socioeconomic status may affect the degree of stress that the families may feel and they cope with these stressors; The hope is that randomization would account for these possible confoun	for confounding = +; randomization would reduce the possibility of confounding if it is done appropriately	an multivariate group comparison (MANOVA) for the quality of life measure; did not mention other analyses but provided t-scores and F values in addition to p-values; they stated that the rest of the analysis will be published when the analysis is completed for all data	AD-scores decreased in control group by 16.2 point and 20.5 points in intervention group (t=1.27, p = 0.21); quality of life results differed from baseline (F = 2.2, p=0.057), marked increase in confidence in medical treatment in the treatment group found to the main reason for this chang	preliminary data shows that intense group interventions may improve disease management by increasing parent's confidence in medical treatment while also addressing the ability of parents to cope with stressors that may relate to their child's illness	validity of the study is good for the information that is provided. Would like to see a table comparing the control and intervention groups.	Validity: may be applicable here in the U.S. if there are English counterparts to the scales and questionnaires used in the study, but there may be some cultural differences that would make it challenging to implement such a program; such an intense program represents a large investment of resources.

	ician, and dietician used over 6 sessions that covered many topics (stress management, daily skin care, general nutrition, food allergies, issues of coping with disease)	had a college or university degree; 15% were single parents; control and intervention did not differ significantly on demographic data (no data or table provided) inclusion criteria was a SCORAD-Score of 20 (used to confirm diagnosis of Atopic dermatitis) with duration of eczema of at				different coping styles)		ders			e through a univariate analysis (F = 7.96, p <0.01); decrease in rumination through the coping styles scale was greater in intervention group (t=2.44, p<0.05)			

		least 3 months; SCORAD-scores at baseline ranged from 20-85 (mean 43.3, SD= 16.5)												

Abstract

Chronic Kidney Disease (CKD) places a significant burden on the pediatric population. Children with this condition require several medications in addition to the possibility of home dialysis and or transplantation. Often their parents are responsible for their care once they are diagnosed, and ideally, the parents will help to transition the youth to adult health services. The degree of knowledge that the parents have regarding CKD can affect the health status of their children, as has been seen in other conditions. This two-prong research includes a systematic review of the literature on the use of interactive media to educate parents about their child's chronic health condition and a qualitative study of parents-youth dyads in the Pediatric Nephrology Clinic at UNC- Chapel Hill. Parents and youth were asked to remember their initial response at the time of kidney disease diagnosis. Additionally we determined which topics parents and youth would want included in a CKD educational game. Parents wanted the game to cover the etiologies of CKD, management, treatment options, nutrition, and laboratory values related to CKD. The children with CKD wanted the game to discuss etiology and symptoms of CKD, and how dialysis treatment feels from the perspective of youth. The parent-youth dyads also provided insight into how a serious game for CKD could be designed, to educate them on this condition and potentially affect health outcomes.

Introduction:

Estimates of children living with chronic kidney disease (CKD) vary from 15-74.7 cases per million children worldwide.[17] In terms of incidence, 6000 children are affected with CKD every year in the United States (U.S).[18] Approximately 5,500 children affected in the United States have end-stage renal disease (ESRD), the most severe form of CKD.[19] This number is of particular interest since dialysis treatment; the standard method used to treat ESRD while

awaiting transplantation, has mandatory coverage under Medicare and acts as a source of financial burden for the government.

Besides being a source of great financial cost for the US health care system, CKD is also a difficult condition to manage since the therapies used to replace kidney function rely heavily on dialysis centers. In the case of peritoneal dialysis, patients and their families have to learn to manage the dialysis treatments at home.

Some of the comorbidities of CKD require patients or their caregivers to perform procedures, such as catheterization or tube feedings. Compounding the issue of procedures and treatment modalities that take hours to complete, patients with CKD have to contend with a multitude of medications, which have side-effects that can complicate their treatment course.

Many chronic conditions in the pediatric population require a child to depend on their parents/caregivers for the majority of their care until the child has developed the skills to independently manage their condition. The important tasks that parents must do for children with CKD include: giving medications at the appropriate times; ensuring that the child attends appointments with providers; and guaranteeing that the child undergoes the appropriate timing for renal replacement therapies. Parents must therefore become knowledgeable about CKD because their skills can drastically affect patient outcomes. The importance of parent health literacy as it relates to health outcomes has been examined, with evidence that low parent literacy is associated with poor health outcomes for the child.[20]

Currently, a web-based educational resource exists for parents of children with CKD.[21] Although this resource exists, it requires a consistent internet connection for parents which they may not have available. Such a website provides specialized lessons about particular aspects of

kidney disease, and is maintained by a reputable source. Although this resource exists, it should not be the sole option for educating parents, and other resources can be developed in the name of educating parents and or caregivers of children with CKD.

Our recent systematic review of the literature showed limited evidence of the use of interactive media in general to educate parents on their child's chronic condition. Another option for educating parents and children is the use "serious games" focused on health. These serious games would focus on providing education regarding a particular health condition. We are aware of no prior studies that address the use of serious games to educate children with CKD and their parents.

We sought to address this gap in the literature through the development of a serious game to educate children and their caregivers on the topic of CKD and its management. The methodology for the development of serious games for the pediatric patient population has been explored before.[22] This particular study aimed to collect the baseline information to gauge interest in a serious game for CKD on the part of parents/children, and to develop potential topics for such a game that parents and patients with CKD deemed to be important for them.

Methods:

Study Design/ Participants: The study used qualitative data collection through focused interviews of children with CKD and one of their parents or caregivers. The study sought to recruit 100 parent-child dyads in order to achieve saturation for the qualitative data that was obtained. This particular paper contains the results of the initial 22 pairs of parents and children.

Study Location: We conducted the focused interviews in the Pediatric Nephrology Clinic at UNC- Chapel Hill. This clinic serves as the referral center for the state of North Carolina, and it has a diverse patient population from the central and eastern portion of the state. The Institutional Review Board at UNC- Chapel Hill approved the study protocol.

Inclusion/Exclusion: We recruited parents and children with at least CKD Stage II (GFR 60-89 mL/min/1.73m^2 or less who were between the ages of 8 and 21 years and spoke English fluently. The age of 8 years was chosen as the lowest accepted age so that adequate responses could be obtained from the children without concerns of cognitive ability. Patients with cognitive impairment based on provider opinion or chart review were excluded.

Recruitment: We obtained a list of potential participants from the electronic medical records (EMR) who fit the eligibility criteria. These potential participants, and their parents, were recruited in the Pediatric Nephrology clinic.

Interviewing: A standardized template was adapted from Sullivan-Bolyai.[23] The questions were shifted to address the issue of knowledge of CKD (Appendix 1). The interviews were conducted in the clinic by either the primary author (AA) or a research assistant. These focused interviews were audio recorded and subsequently transcribed into text documents for thematic analysis. In cases where parents did not consent to audio recording of the responses, notes were taken, and the transcription of these non-recorded interviews was done as soon as possible.

Quality Assurance: The transcripts were reviewed twice and compared with the audio recording to ensure their fidelity. This step also allowed any audible emotional responses to be included into the transcripts so that the maximum breadth of the experience communicated could be captured and assessed.

Analysis: We performed thematic analysis on the transcribed interviews using Atlas T.i. software. Recurring themes were coded and incorporated into super-themes. The coding was performed by AA, with notes made throughout the process of developing the codes themselves. These notes acted as a source for reflexivity, or recognition of the influence that the research brings to the research process. [24]

The coding process was discussed among the investigative team so that consensus was reached on the codes and the themes that were developed. This information was analyzed for overlap between the various codes and super-codes. These super-codes were identified as important areas of focus for parents and are thus relevant to the development of a serious game education about CKD.

Results:

We enrolled 22 parent child dyads, including 9 fathers and 13 mothers (Table 1). The stage of CKD for the patients included Stage 2 (23%); Stage 3 (55%); Stage 4 (4%); and Stage 5 (18%). The associated diagnoses included lupus nephritis, renal agenesis, focal segmental glomerulosclerosis, and sarcoidosis.

Many of the reported themes between the parent and child cohorts overlapped or were similar (Figure 1). Reported themes for the parents included: reaction to diagnosis; learning preferences and sources of information; lessons/experiences; disease management of their child's health; and game, which dealt with the ideas of game use and the ideal game for educating the parents about CKD. Themes for the children included: diagnosis; learning; support; disease management; and the preferred serious game to learn about their diagnosis.

<u>Parent/caregiver Responses:</u>

Diagnosis:

The diagnosis theme included the emotional response of parents to their child's diagnosis, and the supports they had in place after the diagnosis. Parents mentioned family, friends, spouses, church, and providers as their most common support systems. Included in this notion is the idea that providers and hospital staff helped parents better stabilize their emotions.

Parents' emotional responses were primarily focused around the sense of shock upon receiving their child's diagnosis. Their experiences were traumatic, heartbreaking, and overwhelming. The negative experiences include not understanding the diagnosis, fueled by emotions such as confusion. The parents also expressed concerns about their child being different from other children, including their siblings.

However, parental emotional responses were not entirely negative. Some parents commented that it was a relief to have a distinct label for what their child was going through. Additionally, one parent commented on the idea of having to deal with their child's situation in a mature, realistic manner. This parent said,

"It was shocking; I think I blocked it out more than anything thinking it wasn't real. But at the time I realized that it was something that we had to deal with … (PK22)."

Learning:

The sub-theme of learning dealt with how parents learned about their child's condition, in particular the sources of information that were used. In regards to how parents learned about their child's diagnosis, the provider was the main source of information. Parents mentioned that they relied on asking their child's provider and it was important.

"You know I think the primary source of information is definitely physicians, nurses, you know when she was in the acute stage. The secondary source of information would have been internet and specifically patient advocacy websites. There's an HUS[1] support group online that we've gotten a lot of information about kidney related issues long term, initially. And then over time the primary source has been our quarterly visits PK 3)."

This quote also highlights the importance of the next preferred source of information, the internet. Websites that parents visited provided information about long-term care for the child's particular condition. Parents felt that the sites visited were reputable. Another aspect regarding use of online resources was that parents did not simply research their child's disease one time. Attempting to understand the child's condition was an iterative process for the parents. But the information that parents found on sites was not always encouraging for them:

"I Googled it on the internet to see what it was for myself and it was kinda saying that uh a lot of kids get it around his age and it was saying how it comes about when they're maturing from being a little child to a teenager so and I really didn't like a lot of the negative remarks that they had to say (PK21)."

Lessons/Experiences:

[1] Hemolytic Uremic Syndrome

The larger theme of lessons/experiences included: the advice parents had for other parents of children with CKD as well as challenges and responsibilities in caring for CKD. The challenges that parents encountered were centered on the child's condition or emotional challenges for the parents. The responsibilities that the parents perceived included monitoring the child; acting as a support system for the child; sharing responsibilities; and managing CKD.

The parent-to-parent advice sub-theme included the medical aspects of CKD and approaching CKD as an experience in general. The general advice included words of encouragement for the parents to *"try to do your best and work on it (PK17)."* One particular parent provided a comprehensive statement that encompassed the ideas presented by other parents:

> *"To always stay opened minded. Don't think the worse. That was one of the things I did. I always had painted my mom's image of what I had experienced. When we went in and realized what K14 was going to go through, I was like "oh my gosh, no." I closed the doors, I closed myself off, I didn't want to hear any reasons. My husband was like, "hey look, everything is going to be ok." You just got be opened minded. You're going to have to realize that you are not doing this for someone who's going to completely rely on you for the rest of your life. Keep it open-minded, always ask questions. Don't hesitant to…even if it might sound the slight*

dumbest thing, and they had just repeated it three times, if you don't understand it you need to ask. Make them break it down for you…. (PK14)."

The medical-based advice emphasized the need to understand CKD by asking providers for information. The medical and general advice overlapped when parents advised their potential peers to be watchful of their children for changes that may indicate more serious issues, such as symptoms of elevated blood pressure.

Parents reported that keeping a close eye on what their child ate outside of the home was particularly challenging. Parents also mentioned having to monitor their child to make sure they maintained adequate fluid intake and adherence to medications. Transition of responsibility was mentioned by a few parents as they discussed how they were expecting more accountability on part of the child as they got older in managing their condition and its associated obstacles during transition.

Parents' experiences extended beyond simple medication adherence, and they commented on issues such as nutrition and prevention of infections during dialysis treatments. One parent remarked that their role was not singular: *"I pretty much do whatever I can, whatever she needs done (PK19)."*

Disease Management:

The disease management sub-theme included strategies used to manage the child's condition and fell into intrinsic and extrinsic strategies. The intrinsic strategies showed the parents relying on themselves and instincts.

"I don't remember having any strategies; I just remember taking care of him. I don't remember coming up with any, I guess it was more motherly instinct, I don't know. I didn't write anything on a calendar or anything. I did do that for his appointments, I did do that. But everything has been like clockwork. I don't know how to explain that (PK9)."

This response did not encompass the entirety of the approaches used by parents. A few parents had extrinsic strategies such as calendars, pillboxes, and utilized their spouse as an additional assistance.

Game:

Videogame use was prevalent among the parents, including simple games on the phone. Parents reported disparate opinions when asked if they would be interested in a game to learn about CKD. There was a mixed response; a few parents stated a videogame would be useful, while other parents indicated they would not be interested in such a game. The parents who had no interest in using a videogame were asked what it would take to get them interested in this type of serious game. Their response included that having a question-answer component or a highly-interactive game would be more appealing.

Parents mentioned that the design for a potential serious game included topics of nutrition, CKD, and other general issues like the importance of keeping doctors' appointments and skills for parents to manage their child's condition (Figure 2). Nutrition encompassed an

explanation of important food choices, including a list of foods that parents could prepare, and foods that a child should avoid.

Parents mentioned that CKD as an entire topic within the serious game and that it should include: etiology, treatment options, location of information resources, consequences of not following a treatment regimen, understanding lab values, covering specific disease, and issues that need to be addressed for follow-up care. Parents expressed a desire to obtain skills to manage their child's particular disease through the game.

The general topics that were preferred in the serious game extended beyond disease-based information. Parents wanted general health topics, such as staying healthy and monitoring weight, along with the limitations that may be placed on the child because of their diagnosis. While monitoring the disease, parents wanted to learn about warnings signs [symptoms of elevated blood pressure and dehydration] through the game.

Medications were also an important issue for the parents. They perceived that the ideal serious game would include a section outlining the purpose of the different medications. Additionally parents wanted an explanation of how dosing worked with the various medications.

Parents discussed topics of a serious game that they thought were important for their children to learn. Parents wanted their children to understand the anatomical location of the kidney, kidney physiology, and a general overview of what is involved in a kidney transplant. In terms of self-efficacy the parents wanted their child to be aware of side-effects while on medications.

<u>Children Responses:</u>

The children and adolescents with CKD brought up concepts that fell into five larger themes including diagnosis, learning, support, disease management, and the game. Such themes were similar to those found in the parents (Figure 1).

Diagnosis:

The theme of diagnosis dealt with the response to a diagnosis of CKD from the child's perspective. Youth remembered negative emotions, including a sense of shock, fear, nervousness, and feeling that it would be difficult to have a normal life; however, such negative emotions did not dominate the conversation from the children. Self-reliance as a skill was presented through a mature statement by one patient.

"More in shocked in the beginning, but can't do anything about it now so I just kinda make the best of it (K6)."

Learning:

Youth preferred providers as an informational resource, followed by their parents, the internet, books, and pamphlets. The experiences that one patient had with a family member with kidney disease helped.

"Well like I know that it was just like bad cuz my grandma had it so I knew about it but my mom knew more about it cuz she was the one taking care of her so like she already knew how to take care of me (K14)."

Supports System:

The support system in place for youth composed the sub-theme of supports. Youth reported that as they were finding out about their diagnosis, they used friends and family as

support. Specifically, the parents helped youth by providing emotional support and making sure the child was calm, *"My mom was with me the whole time. She was saying everything is going to be ok (K7)."* These supports helped the children cope with their diagnosis.

Disease Management:

When discussing the management of their condition, the youth described skills that were applied by either the children or their parents. The strategies that the children employed to manage their condition included the physical strategies, such as alarms, pillboxes, medication lists, and schedules for their treatment regimens. Youth remarked that their self-care became routine for them, and they found themselves becoming self-reliant over time.

Youth mentioned responsibilities that their parents managing included ensuring that the child was taking their medications. However, the role of the parents, as perceived by youth, extended beyond simply ensuring medication adherences. They also performed many logistical tasks for the children, such as helping the child obtain their medications, transporting the child to appointments, and preparing meals.

Game:

A final theme the children discussed was what they would like included in a serious game for CKD. Comments were made on topics such as general game design, CKD/Kidney- related information, and self-management. The concepts that youth mentioned as important for them in a serious game are in Figure 2. Generally speaking youth were interested in using a serious game to learn about CKD.

Regarding the topic of kidney knowledge, youth wanted the game to cover etiology, stages, and symptoms of CKD. They also desired additional information such as the purpose of kidney transplant and dialysis treatments, how dialysis treatments feel from the perspective of youth, and the consequences of having CKD, including sacrifices that may have to be made as a result of having the condition.

Youth also sought to understand their medications, particularly their purpose and side effects. They brought up the topic of adapting their lifestyle after being diagnosed with CKD, for example, *"something about like how like it's not really hard if you like commit yourself cuz it would be like your lifestyle (K14)."*

Additionally the children wanted the inclusion of self-management skills in the game. The self-management skills would include things that a patient should and should not do because of CKD. Also, children wanted to discuss CKD- related health risks. Children frequently mentioned nutrition and hydration as important topics.

Discussion:

Our study describes novel information offered by parent-youth dyads regarding their learning preferences and desired information for a serious game to learn about CKD. Our focused interviews found a variety of topics that both parents and children found important for understanding CKD and their preferred platforms to learn about this condition.Parents and youth

wanted a serious game to include general information about CKD, such as etiology, stages, and treatment modalities. Children showed particular interest in the experience of dialysis, which speaks to the importance of preparation to receive this treatment. Alternatively, parents seemed to be more interested in the day-to-day aspects of caring for someone with CKD, including following up on instructions from providers.

A serious game intended for educating parents and children requires several characteristics. A particularly important one was entertainment value. Several parents and children stated that they would be willing to use such a serious game if it were entertaining. Entertainment value is important because it may result in greater retention of information. [25]

The use of serious games has been effective in improving outcomes among patients within asthma (knowledge and self-management), diabetes (blood glucose monitoring, glycemic control, and improved disease knowledge), and cancer (medication adherence). [2-5] These improvements are encouraging for the development of a CKD serious game.

The vast quantity of CKD information that the parents and youth wanted included in the game was surprising. Although this information could be provided in clinical visits, it is not always the ideal environment in which to educate the youth and their families due to general time-constraints as well as various medical and social issues that may arise over the course of an appointment. By giving an understanding of the various topics that the child-parent dyads found important, a serious game can function as an educational tool to bridge knowledge gaps.

The quality of the information provided through a serious game" would have to be

substantiated. Advocacy websites are a source of information for parents, but at the same time may provide information that is upsetting to them. As seen in one parent's response, the information that they found on the internet caused emotional distress. The presentation of high quality, timely information through an entertaining game may support parents and children as they cope with the diagnosis of CKD.

The roles that parents perceive for themselves in the management of their child's CKD have been described before. [26] Parents view themselves as "students" who learn from providers. This dynamic appeared in our focused interviews as most parents identified their providers as a primary source of information. While youth report their providers as the main source of health information, they also mentioned their parents as their second trusted source for knowledge about their condition and its management. This novel finding stresses the fact that parents need to become prepared to teach and "train the trainer" curriculums need to be developed. [27]

This study was limited by the age of the children who were recruited as well as the sample size. Youth have their own learning capacities that develop in conjunction with their minds and bodies, so the data collected here represents their own experiences. Since we did not include younger children, we missed out on a unique level of care that may be involved in CKD management, including the requirements for feeding tubes, managing unique formulas, and special fluid needs. These aspects of caring for a very young child with kidney disease would present unique challenges for the parents; and such tasks were not discussed by this cohort.

Conclusion:

Parents and youth prefer to learn about CKD from their health providers. Youth, however, cite their parents as another preferred source of information, pointing out the need to develop a "train the trainer" curriculum for parents of youth with CKD. Given that parents view themselves as students, an effective and valid educational tool is warranted. A serious game intended to educate children who have CKD, and their parents, needs to address several topics. Additionally the game needs to be entertaining for the parents and youth in order maintain their attention. Additionally this education platform can be studied to measure its effect in clinically important outcomes, such as number of hospitalizations and transplant rejection rates.

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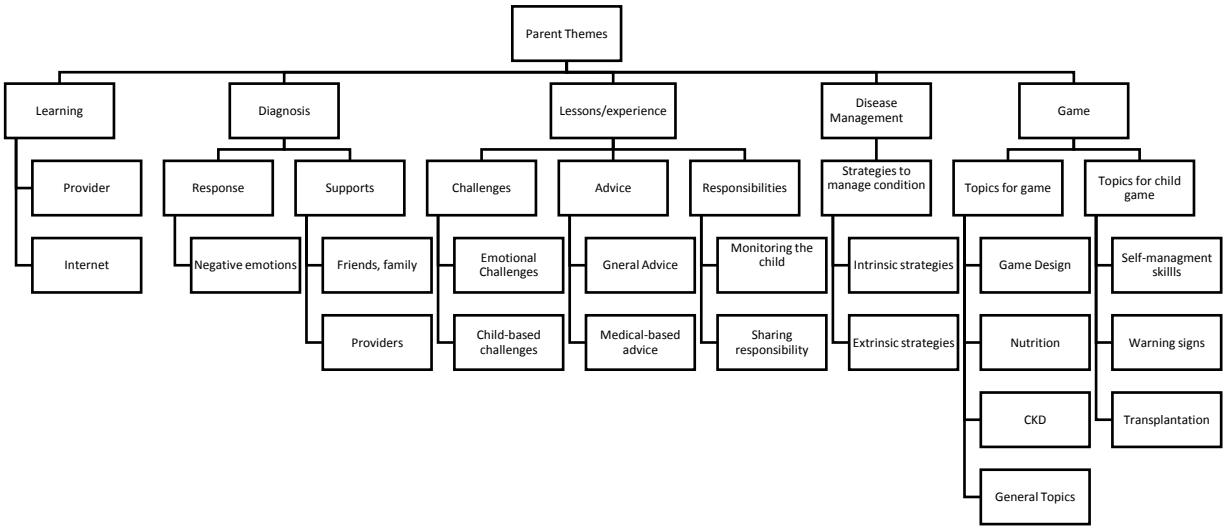
Table 1. Characteristics of participating children

Characteristic	**(% or mean)**
Sex Male Female	 10 (45%) 12 (55%)
Race/ethnicity Hispanic Caucasian African America	 5/22 (23%) 6/22 (27%) 11/22 (50%)
Age *Mean (SD)*	14 (±3) years
Transplant recipients	5/22 (23%)
Age of diagnosis *Mean (SD)*	9 (±5) years
Percentage of life with Diagnosis *Mean (SD)*	38 (±32) %
Number of Prescription Medications *Mean (SD)*	8 (±4)

Figure 1. Major Themes



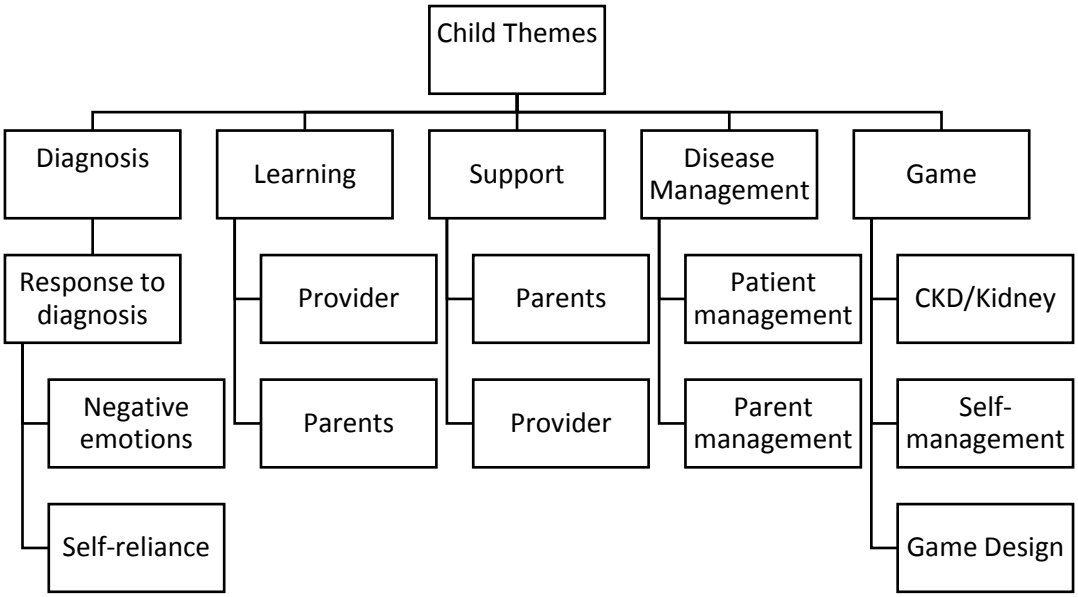


Figure 2. Game Design Topics

Parents:

- Sense of Competition
- Different levels of the game for different literacy levels
  - Answer-question based for those with higher education
  - Pictures and videos those with lower education
- Providing information in laymen terms
- Staying away from sounding like a lecture
- Running through different scenarios
- Need for the game to be entertaining

Children:

- Questions that pop up
- Helping out other children go through transplantation
- Idea of condition improving
- Opinion of someone who has CKD

Appendix 1:

Focus interview questions for Parents:

- Can you tell me what it was like for you upon hearing your child had Chronic Kidney Disease?
- What kinds of supports did you use during the first few months after diagnosis?
- Tell me how you went about learning your child's Chronic Kidney Disease care.
    - Did you use the internet, your physician, or other resources for your information?
- If you have a spouse/partner, please tell me how you decided who would be responsible for each of the required care tasks and responsibilities.
- Can you describe the role you presently play in your child's day-to-day Chronic Kidney Disease management?
- Can you describe the strategies that help you manage your child's Chronic Kidney Disease care?
- What advice would you give to parents who have a young child newly diagnosed with Chronic Kidney Disease?
- Tell me what is the most difficult part of caring for a child with Chronic Kidney disease?
- Have you ever played video games in the past?
    - What about games on your phone, mobile device, or tablet?
- How would you feel about a simple game to help you learn about your child's Chronic Kidney Disease
    - How do you feel about using a simple game to help your child help learn about their condition?
- Would you use an educational game to learn about your child's condition?

    - If you don't think you would use this type of game, what would it take for you to use this type of game?
- What sort of information would you like included in an educational game for your child
    - What sort of information would you like included for a game that you could use to learn about your child's condition?
- Can you think of any topics that you would like included in such a game?

Focus interview questions for Youth:

- Can you tell me what it was like for you when you heard you had Chronic Kidney Disease?
- What kinds of supports did you use during the first few months after diagnosis?
- Tell me how you went about learning your Chronic Kidney Disease care.
    - Did you use the internet, your physician, or other resources for your information?
- Can you describe the role your parents presently play in your day-to-day Chronic Kidney Disease care?
- Can you describe the strategies that help you manage your Chronic Kidney Disease care?
- Have you ever played video games in the past?
    - What about games on your phone, mobile device, or tablet?
- How would you feel about a simple game to help you learn about your Chronic Kidney Disease
    - How do you feel about using a simple game to help you learn about their condition?
- Would you use an educational game to learn about your condition?

    - If you don’t think you would use this type of game, what would it take for you to use this type of game?
- What sort of information would you like included in an educational game for your condition
- Can you think of any topics that you would like included in such a game?